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## **The Habitual Rhythms of Becoming-Involved: Insights into participation experiences in urban spaces by children with diverse mobility**

*Lisa Stafford, Barbara Adkins and Jill Franz*

### **Abstract**

This chapter reports on a study<sup>1</sup> that reveals the essence of participation in urban spaces by ten children who live with various physical conditions: Muscular Dystrophy, Cerebral Palsy, and Autoimmune Rheumatic Diseases. These conditions affect muscle and movement differently resulting in diverse ways in which children move through space (personal mobility). The children at the time of the research were 9-12 years of age residing in South-east Queensland, Australia. The approach and methods selected for this study, interpretive phenomenological inquiry and grounded theory, were chosen for their capacity to capture the complexity and multiple interactions of the child's urban living. The confronting and poignant accounts by children and their families of their experiences produced a new way of understanding the concept of participation, as a 'journey of becoming involved.' Their accounts of performing everyday routines (e.g. leaving home, getting in and out of the car, and entering places) in urban spaces (neighbourhood streets, schools, open spaces, shopping centres, and hospitals) revealed differences in the way settings were experienced. These differences were associated with the interplay between the body, space and context. Where interplays were problematic, explicit decisions about children's involvement were made. These decisions were described in terms of 'avoid going', 'pick and choose', 'discontinue', 'accept', or 'contest.' What these decisions mean is some spaces are avoided, some journeys are discontinued, and some barriers encountered in journeys are normalised as everyday experiences, i.e. 'tolerable discrimination'. These actions resulted in experiences of non-participation or partial-tokenistic participation. The key substantive contribution of the research lies in the identification of points in children's journeys that shape participation experience. These points identify where future interventions in policy, programming and design can be made to make real and sustaining changes to lives of children and their families in geographies crucial to urban living.

**Key Words:** Children, mobility, physical disability, children's participation, urban spaces, embodiment, phenomenology.

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## 1. Introduction

‘Children’s participation’ is a concept widely discussed throughout childhood and urban studies, however what this concept means and how it is experienced by children with diverse abilities is largely unknown in the broad literature<sup>2</sup>. The need to build this knowledge from the direct experiences of children with diverse abilities was also identified, as their voices have often been absent.<sup>3</sup> This paper reveals participation to be a ‘Journey of Becoming Involved’ by children with diverse mobility and their family in their everyday lifeworld. To begin with, the paper will briefly outline the theoretical and methodological approach that informed the study of ‘children’s participation’ before describing the essential qualities of the ‘journey’.

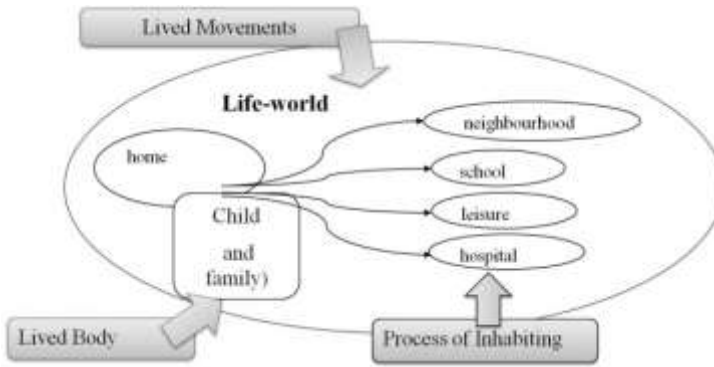
## 2. Theoretical Approach to ‘Children’s Participation’

The emergent interactional model of disability has re-asserted the concepts of the body and embodiment in studying disability and emancipation. Hughes and Patterson<sup>4</sup> view the body as an ‘experiencing agent;’ a ‘site of meaning and source of knowledge about the world’ that aids understanding a person’s embodiment. Shakespeare<sup>5</sup> also believes that focusing on the ‘interaction between the person, the environment and the context holds the key to improving the participation experience of people living with impairment.’ This study brings together three different but related theoretical-philosophical positions that form the framework to understanding participation as a phenomenon of human experience.

The foundational work of Lewin’s<sup>6</sup> study of the person and the environment provides an overarching framework for understanding experience in a holistic and integrative way. Enabling greater scrutiny of the person as body is Merleau-Ponty’s<sup>7</sup> concept of the habitual body (body-subject): ‘I am conscious of my body via the world and I am conscious of the world through the medium of my body.’ According to Merleau-Ponty our point of reference in the world is through our corporeal schema (body-subject), which guides our body’s movement unthinkingly.<sup>8</sup> Conflict encountered between one’s habitual body and the body-in-moment can immobilise one’s motility and profoundly disturb our reference in one’s world when the body cannot adjust unthinkingly.<sup>9</sup>

How children live with their world is understood from the perspective of Geographical Phenomenology. Seamon’s<sup>10</sup> typology of ‘habitual movements of everyday life’ (Body Ballet, Time, Space, Body Routine, and Place Ballet) helps to reveal our sense of place in our world. The concept of sense of place is further understood through Relph’s<sup>11</sup> model of Insideness/Outsideness. In conjunction, Lang’s<sup>12</sup> concept of Inhabiting helps to reveal intentionality to transform space to place by children and their families through the act of incorporation. Combined,

these phenomenological concepts (refer to Image 1) provide a means to reveal and understand ‘children’s participation’ as a whole experience.

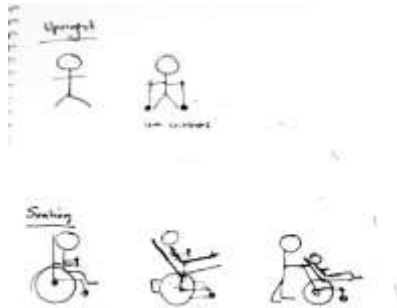


**Image 1:** The applied phenomenological lenses.  
Image courtesy of Lisa Stafford.

### 3. Method

Three research questions framed the approach and analysis: 1) what are the different ways children experience participation in urban spaces; 2) how are these differences in participation (re)produced through body-space interactions; and 3) why do children with disabilities experience what they do? The methodologies, the Interpretive Phenomenological Lifeworld approach<sup>13</sup> and Grounded Theory,<sup>14</sup> were adopted to reveal the implicit meaning of children’s participation from everyday experiences in their world. Together, they provided the capacity to capture the complexity, differences and multiple interactions of body-space-context that are experienced in the urban world, and in doing so, help generate new knowledge.

The child participants were theoretically sampled to attempt to reflect the diversity in mobility that exists within the label ‘physical disability’. Non-government organisations provided access and in-kind support with recruitment. The ten children represent five ways in which the body moves through space (habitual mobility): walks unaided ( $n = 2$ ), walks but tired over distances ( $n = 2$ ), walks with crutches ( $n=1$ ), moves by self-driving power wheelchairs ( $n=4$ ); and moves by manual wheelchair pushed by others ( $n = 1$ ) (refer to Image 2).



**Image 2:** Diversity in bodies and mobility of the participants.

Image courtesy of Lisa Stafford.

The six children who used mobility aids habitually, revealed they regard these aids as part of their body, their ‘habitual body,’ as is illustrated by P1.<sup>15</sup>

Int: Ok, so we would use one of these then? [showed wheelchair picture]

P1: No, we walk.

M1: Yeah but you use a wheelchair.

P1: Oh yeah, oh so that’s my wheelchair?

Int: Yeah.

M1: You wheel down, you don’t walk?

P1: Oh, that’s silly.

The diversity of the children and their needs informed the design and delivery of the data generation, specifically the need to, accommodate the range of physical needs, be sensitive to the physical and emotional comfort of participants, accommodate the many ways in which children express themselves.<sup>16</sup> Consent gathering was undertaken in the pre-interview meeting, which also enabled specific needs of children to be identified in order to further adapt methods.

Data generation occurred over three visits in 2010-11 within the children’s homes and were designed and implemented as activity-based interviews<sup>17</sup> (refer to Image 3) to elicit meaning and felt experience as understood by the participants. The semi-structured interviews occurred throughout each activity and were built upon over the course of the research.



Activity 1: Activity Book



Activity 2: Mapping



Activity 3: Designing



Photographs of body ballets

**Image 3:** Activities used in data generation.

Image courtesy of Lisa Stafford.

Data analysis was undertaken using a grounded theory coding process and phenomenological lifeworld approach to identify themes, meaning and interconnections emergent from the narrative in the data. The final purpose of the analysis was to uncover the essential phenomenological meaning; in this case this meant reaching an understanding of participation as a *journey of becoming involved*:

Int: It's really about capturing what the problem is; you can't just deal with one thing and not the other as we were talking about. It's a journey and it's capturing that and what are still the issues.

M5: Yes it becomes one whole picture.

#### 4. Journey of Becoming Involved

The accounts of performing everyday routines (e.g. leaving home, getting in and out of the car, and entering places) in urban spaces (neighbourhood, street, school, open spaces, shopping centres, and hospital) reveal that the phenomenon of participation is understood as a *journey of becoming involved*. The structure of meaning of the 'journey' consists of performing four sequential and interdependent lived movements (pre-journey, onset, gaining entry, once inside spaces outside the

family home) to inhabit urban spaces. In reflecting on their experiences, the children revealed that their embodiment of these habitual routines is never straightforward or easy because their corporeality was often made problematic in terms of the spatiality of the situation. These felt differences are highlighted throughout this ‘journey.’

Starting at home, the *Pre-Journey* lived movement involves planning and thinking about going out because past encounters of inhabiting and participating in spaces were difficult and at times immobilising. Deciding whether to *avoid* going out or go out by *finding a way* or *picking and choosing* where to go, is based on a number of considerations, as illustrated by M5: ‘Is it going to be suitable when you get there, for not just places in the community but people’s home and you know if it doesn’t suit you don’t get to go, or someone doesn’t get to go anyway.’ Up to 10 considerations were located in their accounts that needed to be thought through and weighed up to make decisions, particularly in non-compulsory environments such as leisure pursuits, social outings or to run errands (see Table 1).

**Table 1:** Conditions influencing the decision to go out.

Conditions	
Value of going	Time
Alternatives	Spatial mobility
Past Experience	Physical Form and layout
Resources	Distance
Conveniences	Climate

In deciding to go out, the next part of the journey is the physical act of getting out the door (*Onset lived movement*), which involves two body ballets: *Leaving the Door* and *Getting into the Car*. The physical act of leaving the door was found to be dependent on others due to their physical needs and no access to assistive technologies, such as environmental control units, which enable their autonomy to open doors. The novelty of having the freedom to open the door through the use of assistive technology is illustrated by P2/M2:

Int: Like open a door?  
M2: Yeah, like x does in America. Their whole house has the button...you [P2] sat there all afternoon...thinking it was great that you could open and close doors and run in and out of the house.

Once outside the door the next task is to load into the vehicle. For children who embodied wheelchairs, their body ballet is revealed as more time-intensive and different depending on the type of family vehicle. For example, P2 and P1 had a family vehicle that accepted their habitual body, whereas P4, P5 and P7 did not

have an accessible family vehicle that accommodated their habitual body. In the latter case, the parents described the act of ‘transferring,’ as having to manually lift the child out of their wheelchair and move them into the back seat of the vehicle, an act described as increasingly difficult with their growth in age and weight. The cumbersome ballet was found to invariably influence the occurrence of going out, as illustrated by D1:

D1: ...I just don’t know how we got along for so long without it. ...transferring to the manual chair... little things like being about to go out to dinner or lunch or to the café it was too much hassle before.

The interaction between the family vehicle and child’s body was revealed as a critical point located in their journey, having an impact on both the child’s and their family’s motility.

Once on the journey, the next lived movement performed is *gaining entry* to the intended space. The first body ballet, *finding a car-park*, was not a straightforward act if requiring a wheelchair-accessible car parking bay. Three problems make the act difficult: the design of the car park, number of allocated wheelchair-accessible parks, and parks taken by people without permits. P4 illustrates the felt impact of such an act: ‘...people just go in the disabled parking cause they think normal parking, they just think they can just park there whenever they want.’

Using standard parking bays is not an option for 6 of the children (P1, P2, P4, P5, P7, P8) because the bays are not wide enough:

M7: It’s hard getting him out of the car without a wider park. Because P7 Is not transported in his chair, he sits in a car seat. Getting in and out is a drag.

When unable to find a suitable and safe car-park to get in and out of, the journey may be discontinued, as illustrated by P2’ mother:

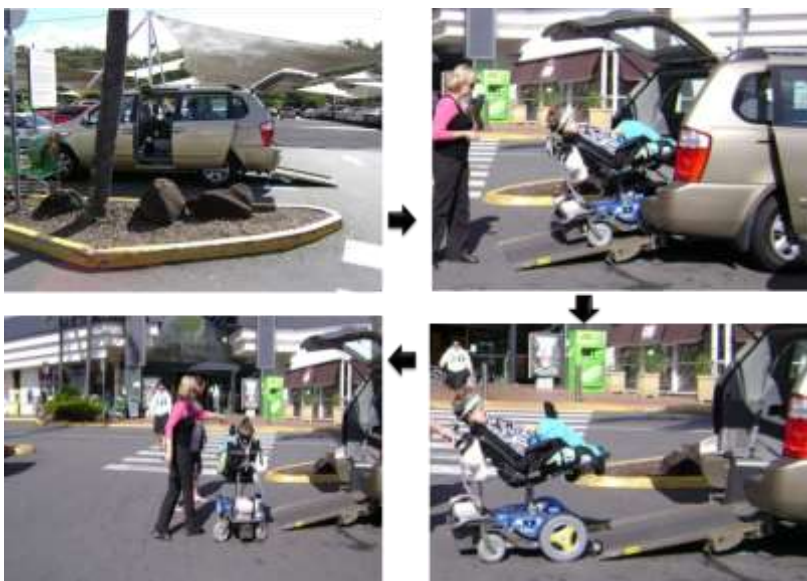
M2: I have been to the shops with P2 and I have not been able to get a park where it was not safe enough to unload P2 and we’ve had to come back.

When the car-park can be navigated, the body ballet of getting out of the car is performed.

The changeable conditions and hazards associated with the spatiality of the situation meant the act was, at times, felt to be ‘dangerous’ and ‘ridiculous,’ as illustrated by P2: ‘like today like, I had to get out and then turn around and I was in the middle of the road where I was about to get hit.’ Image 4 captures p2 performing the body ballet in a local carpark, as well as the act of the ‘human



shields;<sup>18</sup> employed by parents and/or carers as a mitigation strategy to reduce the risk of the child being hit in shared spaces with vehicles.



**Image 4:** Performing the dangerous ballet at P2's regular hangout.  
Image courtesy of Lisa Stafford.

When the child/family happens to get out of the car, the next body ballet is *getting inside* the spaces, which is felt to be complicated, lengthy and/ or hazardous due to multiple hazards (e.g. objects, other people's behaviours, poor design). For example, P8 describes the impact of a long walk to the entry, which has been referred to by participants as the 'long way around:'

The disabled parking is suppose to be close ...It is over there and I can't, by the time I get there its like oh my god this is suppose to be disabled parking. By the time I get there I'm poufed [tired].

The pedestrian's path of travel from outside to inside was often felt to lack thought from developers and designers, particularly about how people moved through space. This is captured by M5 and Image 6:

...the access for pedestrians there is just ridiculous. Their footpaths at the front of shops are narrow and there are some parts where it says no pedestrians, yet they are footpaths and I don't understand that.



**Image 5:** Movement through space by pedestrians, a design afterthought.  
Image courtesy of Lisa Stafford.

The lived movement of gaining entry was another critical point in their journey and was revealed to influence the (re)production of differences in their experiences. This is illustrated through the acts and decisions performed by the families, such as the decision to 'avoid going,' as illustrated by M4:

M4: What this means to us [our family] is that it makes it so difficult to take P4 to the shops. We avoid it. ...and I try never to go to the shops with the kids unless I have to take them.

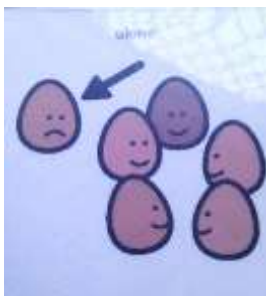
Another strategy employed by families to ensure their appearance in the urban world, is to tolerate discrimination as part of everyday life:

M2: ....I guess what happens is you just end up getting over the hurdles and you don't see it them as hurdles any more. And if something is easy, you're like oh my goodness that's easy, it's a bonus.

When one does gain entry, the next movement is becoming involved within the space. A critical point tied to one's affordance of genuine participation, is the felt responsiveness of the space to the needs of the children and their families. Four features shape this: the rules, the physical form, resourcing (knowledge, support, equipment/technology, time), and actions of others. An example of affordance was revealed by P7, who described having the opportunity to compete in the school's

400m running race alongside his peers by his habitual way (body + power wheelchair) and how this involvement evoked a sense of existential insideness.

Unfortunately, experiences of genuine-participation were not frequently encountered, as the children's environment(s) were often not responsive to their needs, contributing to partial or non-involvement. Both types of non-genuine participation were considered boring by the children: 'it's boring watching others (P1),' and could also evoke a sense of existential outsidership, as captured by p7's feeling of 'alone (see Image 6).' In summary, the findings presented here provide an insight into children's everyday journeys of becoming involved in the urban-world.



**Image 6:** Existential outsidership felt from being denied entry.  
Image courtesy of Mayer-Johnson LLC.<sup>19</sup>

## 5. Discussion and Conclusion

The lived problematic encounters located throughout the journey of the eight children participants were critical points in shaping their felt experiences. The children and their families felt that these difficulties were because of how others and systems perceive their body. For example, those with visible physical conditions felt that they were often overlooked because of assumptions about their capacity or safety, whereas those with invisible conditions, such as juvenile idiopathic arthritis, reported being disbelieved as to their felt fatigue and pain in performance.

Studies by both Scully and Tombs<sup>20</sup> reveal how one's value and recognition is tied to the corporeal form. They illustrate how 'normal' corporeal form (upright forward facing adult body) is assigned value and autonomy,<sup>21</sup> where bodies that vary from this norm lose autonomy and value. Such perceptions influence the spatiality of the situation, which impact on one's motility and level of involvement in opportunity, affordance, enjoyment and/ or sense of place, as illustrated by children and their families in this study. There are many implications of the findings; one critically important implication is that an understanding of the

experience of children with diverse mobility requires us to move beyond discourses of ‘participation’ to the spatial, temporal and embodied dimensions of everyday urban life. This paper illustrates that together these perspectives allow us to see the crucial role of unnoticed aspects of everyday experience as crucial to urban life. The embodiment of the wheelchair, the experiences of entering or leaving houses and cars stand as examples of these experiences. These insights require three reframes: reframing the body-in-space to reflect the diversity of the corporeal form and movement, reframing the social group childhood to reflect the heterogeneity of this group, and reframing participation to reflect both the becoming and being involved that forms the whole experience.

There is so much more to learn about children’s participation. However this study has made a contribution to understanding participation as a holistic phenomenon grounded in the everyday encounters of children with diverse mobility. The illumination of the critical points in the (re)production of differences in experience locate where future interventions in policy, programming and design can be made to make real and sustainable changes to lives of children and their families in geographies crucial to urban living.

## Notes

<sup>1</sup> The research presented here is from Lisa Stafford’s PhD thesis: Lisa Stafford, ‘The Journey of Becoming Involved: The Experience of Participation in Urban Spaces by Children with Diverse Mobility’ (PhD thesis, Queensland University of Technology, 2013), [http://eprints.qut.edu.au/62841/3/Lisa\\_Stafford\\_Thesis.pdf](http://eprints.qut.edu.au/62841/3/Lisa_Stafford_Thesis.pdf).

<sup>2</sup> Snaefridur Thora Egilson and Rannveig Traustadóttir, ‘Theoretical Perspectives and Childhood Participation,’ *Scandinavian Journal of Disability Research* 11, no. 1 (2009), 51-63; Shannon Moore, Luke Melchior, and John Davis, ‘Me and the 5 P’s: Negotiating Rights-Based Critical Disabilities Studies and Social Inclusion,’ *International Journal of Children’s Rights* 16, no. 2 (2008): 249-262; Bill Hughes, Rachel Russell and Kevin Patterson, ‘Nothing to be had “off the peg”: consumption, identity and the immobilisation of young disabled people,’ *Disability & Society* 20, no. 1 (2005): 3-17; Laura Middleton, *Disabled Children: Challenging Social Exclusion* (Oxford: Blackwell Science, 1999), 121.

<sup>3</sup> Michelle Pyer, John Horton, Faith Tucker, Sarah Ryan, and Peter Kraftl, ‘Editorial: Children, young people and “disability”: challenging children’s geographies?’ *Children’s Geographies* 8, no.1 (2010): 1-8; John Davis and Nick Watson, ‘Disabled children’s rights in everyday life: Problematising notions of competency and promoting self-empowerment,’ *The International Journal of Children’s Rights* 8 (2001): 211-228; Mark Priestley, ‘Childhood Disability and Disabled Childhoods: agendas for research,’ *Childhood* 5, no. 2 (1998): 207-223;

Melinda Jones and Lee Ann Basser-Marks, 'Beyond the Convention on the Rights of the Child: The Rights of Children with Disabilities in International Law,' *The International Journal of Children's Rights* 5, no. 2 (1997): 178.

<sup>4</sup> Bill Hughes and Kevin Patterson, 'The Social Model of Disability and the Disappearing Body: Towards Sociology of Impairment,' *Disability & Society*, 12, no. 3 (1997): 329.

<sup>5</sup> Tom Shakespeare, *Disability Rights and Wrongs* (Oxon: Routledge, 2006), 60.

<sup>6</sup> Kurt Lewin, *Field theory in social science: Selected theoretical papers* (1951, Harper & Brothers; re-issued Washington: APA, 1997); Kurt Lewin, *Resolving Social Conflict: Selected Papers on Group dynamics* (1948, Harper & Row; re-issued Washington: APA, 1997).

<sup>7</sup> Maurice Merleau-Ponty, *Phenomenology of Perception*, trans. Colin Smith (London: Routledge & Kegan Paul, 1962), 82.

<sup>8</sup> Taylor Carman, 'The Body in Husserl and Merleau-Ponty,' *Philosophical Topics* 27 2 (1999): 205-226; David Cerbone, *Understanding Phenomenology* (Durman, GB: Acumen, 2006); Dermot Moran, *Introduction to Phenomenology* (London: Routledge, 2000).

<sup>9</sup> Helena Sunvisson, 'Research and ontology: Neurology and Parkinson's disease suffers' lived experiences of embodiment and dwelling in lifeworlds,' in *An interpretive phenomenology in health care research: studying social practice, lifeworlds, and embodiment*, eds. Garrett Chan; Patricia Benner, and Karen Brykczynski (Indianapolis, US: Sigma Theta Tau International, 2010), 59-73.

<sup>10</sup> David Seamon, 'Physical Comminglings: Body, habit, and space transformed into place,' *Occupation, Participation and Health* 22 (2002): s44.

<sup>11</sup> Edward Relph, 'Reflections on Place and Placelessness,' *Environmental & Architectural Phenomenology Newsletter* 7, no. 3 (1996), accessed 20 February 2013, <http://www.arch.ksu.edu/seamon/Relph96.htm>; David Seamon and Jacob Sowers, 'Place and Placelessness, Edward Relph,' in *Key texts in human geography*, eds. Phil Hubbard, Rob Kitchin, and Gill Valentine (London: Sage, 2008), 43-51.

<sup>12</sup> Richard Lang, 'The Dwelling Door: Towards a Phenomenology of Transition,' in *Dwelling, Place, Environment: Towards a Phenomenology of Person and World*, eds. David Seamon and Robert Mugeraue (New York, NY: Columbia University, 1985), 201-213.

<sup>13</sup> see Van Manen, *Researching Lived Experience*, and Dahlberg et al., *Reflective Lifeworld Research*.

<sup>14</sup> See Kathy Charmaz, *Constructing Grounded Theory*.

<sup>15</sup> Participants are referred to as P1 to P10 to aid anonymity; however P2 waved this with the consent in the use of images; however that is only to the people who know him, and hence he is still referred to as P2.

<sup>16</sup> Method and tool development were guided by various scholars, such as: Elizabeth Graue and Daniel J. Walsh, *Studying Children in Context. Theories, Methods, and Ethics* (California: Sage, 1998), 92; John Davis, Nick Watson and Sarah Cunningham-Burley, 'Disabled Children, Ethnography and Unspoken Understandings: The Collaborative Construction of Diverse Identities,' in *Research with Children: Perspectives and Practices*, eds. Pia Christensen and Alison James Alison (New York: Routledge, 2000), 220-238.

<sup>17</sup> Activity based interviews designed by Stafford: Activity 1 – My Urban Habitat Book, Activity 2 – My Urban Habitat Map; and Activity 3 – My Ideal Urban Habitat.

<sup>18</sup> The human shield is where parent and/or carer places their body between cars and the children as a mitigation strategy.

<sup>19</sup> The Picture Communication Symbols ©1981–2011 by Mayer-Johnson LLC. All Rights Reserved Worldwide. Used with permission. Boardmaker® is a trademark of Mayer-Johnson LLC.

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<sup>20</sup> Jackie Scully, 'Disability and the Thinking Body,' in *Arguing about Disability: Philosophical Perspectives*, eds. Kristjana Kristiansen, Simo Vehmas, and Tom Shakespeare (Hoboken, NJ: Routledge, 2008), 57-73; Kay Toombs, 'Taking the Body Seriously,' *Hastings Center Report* 27, no. 5 (1997): 39-43; Kay Toombs, *The Meaning of Illness: A Phenomenological Account of Different Perspectives of Physician and Patient* (Dordrecht: Kluwer, 1993).

<sup>21</sup> Yi-Fu Tuan, *Space and Place: The Perspective of Experience* (Minneapolis, MN: University Of Minnesota, 1977), 45; Kim Dovey, *Framing Power: Mediating Power in Built Form* (Oxon: Routledge, 1999), 49; Rob Imrie, *Disability and the City: International Perspectives* (New York, NY: Sage Publications Ltd., 1996), 80-89.

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